

Effect of the Integrated Prospective Payment Program on Family Members' Knowledge and Acceptance of Hospice Care of Patients on Prolonged Mechanical Ventilation

Chin-Jung Liu, Pei-Tseng Kung, Chia-Chen Chu, Wen-Yu Chou, Chuen-Ming Shih, and Wen-Chen Tsai

BACKGROUND: We sought to evaluate the effect of an integrated prospective payment program (IPP) on knowledge of hospice care and willingness to participate in hospice care among family members of patients on prolonged mechanical ventilation (PMV). **METHODS:** Between November 2013 and April 2014, we used paper-based survey questionnaires from 64 institutions to evaluate knowledge, willingness, and related factors among the main caregivers of patients on PMV regarding hospice care and to determine whether their decisions for the patients were affected by the IPP. **RESULTS:** The average ages of the respondents and patients on PMV were 51.9 y and 70.8 y respectively; 70.6% of the respondents knew about the Hospice Palliative Care Act (HPCA), and 42.3% of the medical staff had introduced hospice care-related information to patients and caregivers in Taiwan. Among the caregiver respondents, 67.6% agreed to write a letter of intent regarding the choice of hospice care or limited life-sustaining treatment. In total, 66.2% (16.1 + 50.1%) of the respondents agreed to hospice care for their family members (ie, the patients on PMV) when the condition was terminal. The factors of greater HPCA knowledge among the patients on PMV were IPP participation, female sex, and coma status. Factors leading to higher levels of HPCA knowledge included age \geq 65 y being married, higher income, awareness of the law, and being introduced to hospice care by medical staff. **CONCLUSIONS:** High levels of hospice care knowledge were unrelated to willingness to participate. HPCA knowledge was greater in the IPP group than in the non-IPP group; however, there was no significant difference in the willingness to agree to hospice care. It is recommended that individuals be encouraged to express their medical decisions. *Key words:* hospice care; withholding life-sustaining treatment; WLST; prolonged mechanical ventilation; HPCA; integrated prospective payment program; IPP. [Respir Care 2020;65(4):464–474. © 2020 Daedalus Enterprises]

Introduction

Prolonged mechanical ventilation (PMV) is defined as continuous mechanical ventilation exceeding 21 d for

> 6 h/d.^{1,2} The incidence of PMV is 5.5% in the United States,³ 6.3% in the United Kingdom,⁴ 9.3% in Brazil,⁵ 11% in Canada,⁶ 20–25% in Taiwan,⁷ and 36.1% in mainland China.⁸ To control medical expenses and increase the liberation from mechanical ventilation, the United

Ms Liu is affiliated with the Department of Public Health and School of Nursing, and Ms Chou and Dr Tsai are affiliated with the Department of Health Services Administration, China Medical University, Taichung, Taiwan, Republic of China. Ms Liu and Dr Chu are affiliated with the Department of Respiratory Therapy, Dr Kung is affiliated with the Department of Medical Research, and Dr Shih is affiliated with the Department of Pulmonary and Critical Care, China Medical University Hospital, Taichung, Taiwan, Republic of China. Dr Kung is also affiliated with the Department of Healthcare Administration, Asia University, Taichung, Taiwan, Republic of China.

Ms Liu presented a version of this paper at the 2018 American Association for Respiratory Care Congress, held December 4-7, 2018, in Las Vegas, Nevada.

This study was supported by grants from the National Health Insurance Administration, Taiwan, China Medical University, and Asia University (DOH102-NH-9009, CMU106-ASIA-13). The authors have disclosed no other conflicts of interest.

States,^{9,10} Taiwan,^{7,11,12} and Europe^{4,13} have established weaning centers to actively wean patients from mechanical ventilation. The increasing number of patients on PMV is a common global problem. Zilberberg et al¹⁴ estimated that PMV in the United States will double from 2008 to 2020. In Taiwan, the number of patients who applied to join the integrated prospective payment program (IPP) to waive co-payments was 7.24 times greater in 2009 than the number in 1995.¹⁵ Previous studies have shown that patients on PMV were older than average^{16,17} and had poor quality of life,¹⁸ with significant burdens on them and their families.¹⁹

Of note, another investigation in Taiwan found that only 29% of 100 subjects on PMV in 9 respiratory care institutions were alert and oriented.¹⁶ Medical decision-making for patients on PMV with altered mental status has become a significant problem for their family members. Prior to 2000, the incidence of PMV in Taiwan was 15%, and its cost accounted for 3% of total health care expenses in 1997. Taiwan's National Health Insurance implemented an integrated delivery system of an IPP for patients on PMV in July 2000, which combines a payment and management care system to resolve the ICU bed shortage.

To respect the willingness to receive medical treatment of those with terminal illnesses and to protect their rights, the Hospice Palliative Care Act (HPCA) was enacted in June 2000 in Taiwan.²⁰ The HPCA supports physicians in the provision of treatment to decrease the signs and symptoms of terminal illness in patients who experience pain and other problems related to their physical, psychosocial, and spiritual well-being.^{20,21} However, for medical staff in certain cultures faced with patients for whom further care is futile, withholding or withdrawing life-sustaining treatment is perceived very differently. For example, this type of decision is well accepted by Western physicians,²²⁻²⁷ but Asian physicians tend to be more accepting of withholding such treatment and less accepting of withdrawing treatment that is already in place.²⁸ Nurses in Europe²⁹ and Australia³⁰ tend to be more accepting of withholding or withdrawing life-sustaining treatment, whereas Turkish³¹ and Iranian³² nurses' attitudes range from negative to neutral regarding the use of life-sustaining treatments.

Elderly Chinese often depend on family members to help them make decisions. One investigation of invasive examination and treatment consent of emergency hospital patients in a hospital in Taiwan reported that, even when subjects were fully awake, only 38.76% signed consent them-

QUICK LOOK

Current knowledge

Medical decision-making for unconscious subjects on prolonged mechanical ventilation (PMV) has become a problem for family members and medical care providers in terms of financial impact and emotional burden. In addition, the concept of withholding or withdrawing life-sustaining treatment from patients for whom further care is futile, is perceived differently across cultures. Making this even more challenging is the lack of understanding of hospice palliative care and end-of-life care planning.

What this paper contributes to our knowledge

We evaluated the effect of an integrated prospective payment program (IPP) on knowledge of hospice care and willingness to participate in hospice care among family members of patients on PMV. Knowledge of hospice care was greater in the group that participated in the IPP than in the non-IPP group; however, there was no significant difference in the willingness to agree to hospice care. Individuals should be encouraged to express their medical wishes in advance whenever possible.

selves.³³ In addition, another study³⁴ reported that only 28% of terminal cancer patients in central Taiwan had given consent for a do-not-resuscitate order themselves, and that most decisions were made by family members.

No study has compared the effect of an integrated delivery system on the knowledge of and willingness to use hospice palliative care (hospice care) for family members. Therefore, between November 1, 2013, and April 15, 2014, we investigated the knowledge and willingness (and related factors) of patients on PMV with and without use of the IPP.

Methods

The IPP program is a step-down care procedure for patients on PMV. The IPP program established respiratory care centers and respiratory care wards. Respiratory care centers only receive mechanically ventilated patients who stayed in ICUs for up to 21 d or who were clinically stable after ventilator liberation. Respiratory care wards receive patients from ICUs or respiratory care centers who required PMV or stayed in a respiratory care center for ≥ 42 d. The insurance payments also decreased from ICUs to respiratory care wards or respiratory home care.² Because the IPP is a demonstration program, institutions can choose whether to join. Therefore, patients staying in in-

Correspondence: Wen-Chen Tsai DrPH, Department of Health Services Administration, China Medical University, 91 Hsueh-Shih Road, Taichung, Taiwan 40402, Republic of China. E-mail: wtsai@mail.cmu.edu.tw.

DOI: 10.4187/respcare.06934

stitutions that had not joined the program did not enroll in the IPP. We hypothesized that increased family member awareness of hospice would lead to greater willingness to provide hospice care to patients on PMV. We also hypothesized that the families of IPP patients on PMV would be less willing to accept hospice care than those in the non-IPP group.

Questionnaire Development

We reviewed respiratory care research, the HPCA, and the literature on knowledge, attitudes, and behavior patterns, and then organized and summarized the information. We invited 10 experts in the field of PMV patient care from northern, central, and southern Taiwan from each type of institution. The primary family members of 3 patients on PMV and 3 nursing staff members from the same respiratory care ward formed a focus group to identify the structure and content of questionnaire variables. The content of the questionnaire included respondent characteristics, characteristics of patients on PMV, respondents' knowledge of hospice care and willingness to engage, and relevant information on mechanical ventilation. Twelve questions were designed for the third part of the questionnaire, including 2 questions related to the hospice care experience, 8 knowledge questions, and 2 willingness questions. After the expert test, family members answered the questions; answers had to match the HPCA to be considered correct.

We used a true/false evaluation scale to measure the knowledge aspects and a Likert scale to measure aspects related to willingness. We invited 5 experts to assess the questionnaire to determine content validity following completion of its design. The content validity index was 0.73–1.00 (average 0.96). The reliability of the questionnaire was measured using the Kuder-Richardson formula 20, yielding a coefficient of 0.78 after the questionnaire was tested.

Questionnaire Delivery

From each hospital level (ie, medical central, regional hospitals, and district hospitals) and chronic PMV care units in northern, central, and southern Taiwan, we included family members of patients ≥ 17 y old who received continuous mechanical ventilator support for ≥ 21 d. The questionnaire was conducted at a ratio of 3:2 between the IPP and the non-IPP groups; 90 questionnaires were collected from the IPP system hospitals, and 60 were collected from the non-IPP hospitals in each area. After obtaining the consent of the institution and the hospital, the IPP case manager was invited to screen out the respondents who had family member care at hospital and at home, institution or at home and to obtain the consent of the patients' family members. The included subjects were asked to complete a questionnaire. This study was approved by

the institutional review board of China Medical University Hospital (CMUH102-REC3-105).

Statistical Analysis

We used *t* tests and chi-square tests to compare the characteristics of patients on PMV in terms of characteristics, mechanical ventilation status, and the differences between respondents in knowledge and willingness based on whether the patient was enrolled in the IPP program. In addition, the total score for knowledge of hospice care had 8 scenario questions, with 1 point for the correct answer and 0 points for incorrect or unknown answers. After the scores for the 8 questions were added, the total score was converted into 100 points for each subject. The following factors were used as independent variables: characteristics of mechanically ventilated patients, use of mechanical ventilation and care status, impact of mechanically ventilated patients on the lives of their caregivers, characteristics of family caregivers, whether the patients were in the IPP, current care institutions and attributes, and hospice care experience. The institution was used as the cluster variable for multiple regression analysis using generalized estimating equations to explore the relevant factors affecting the knowledge of hospice care among family members who are the primary caregivers of patients on mechanical ventilation with a prospective payment program at each care stage. Finally, the "willingness to sign the informed consent form for hospice palliative care" (with 5 total points) was used as the dependent variable; the characteristics of patients relying on mechanical ventilation, the use of mechanical ventilation and care status, the impact of patients relying on mechanical ventilation on the life of caregivers, the characteristics of family caregivers, whether the patients were on the IPP, the current care institution and its attributes, the hospice care experience, and awareness of hospice care were used as independent variables for the multiple regression analysis using generalized estimating equations and the Wilcoxon rank-sum test. This analysis was performed to explore the relevant factors affecting the willingness for hospice care in family members who were the primary caregivers of mechanically ventilated patients at each care stage. We considered $P < .05$ to be statistically significant. Statistical analysis was performed with SAS 9.4 (SAS Institute, Cary, North Carolina).

Results

Respondent Characteristics

A total of 687 eligible respondents from 64 institutions (6 medical centers, 11 regional hospitals, 23 district hospitals, 15 nursing homes, and 9 home care centers) were included in this study, which took place from November 1,

2013, to April 15, 2014. A total of 601 questionnaires were completed (87% response rate), with 49.3% male and 50.8% female respondents. There was no difference between the respondents with and without the IPP, with the exception that the non-IPP respondents had higher monthly expenses (Table 1).

The average ages of the respondents and patients on PMV were 51.9 y and 70.8 y respectively. In total, 54.7% of the patients on PMV were the respondents' parents, and 61.2% of patients were comatose (32.3%) or semi-comatose (29%; ie, defined as comatose patients who can be aroused to consciousness using various stimuli). Ventilator ownership was significantly different between the IPP and the non-IPP groups; most ventilators were supported by a hospital or institution (93.3%); however, more individuals in the non-IPP group owned their ventilator than those in the IPP group. The IPP group had a longer duration of mechanical ventilation each day at 22.5 ± 4.4 h versus 20.9 ± 5.8 h at night ($P < .001$), and 89.1% of the IPP group was able to waive co-payments, compared with 69.1% in the non-IPP group ($P < .001$) (Tables 1 and 2).

The Knowledge and Willingness for hospice care

In total, 424 (70.6%) respondents had heard about the HPCA. Only 254 (42.3%) medical staff members had provided information about the HPCA. The average knowledge score was 51.35 ± 29.5 . The respondents who were involved in at-home care and respiratory care ward care had the highest knowledge scores (ie, 56.4 ± 24.91 points and 53.92 ± 30.8 points, respectively). Lower knowledge scores were observed among the respondents from respiratory care centers (ie, 48.1 ± 29.4 points) and ICUs (47.0 ± 31.8 points). A total of 406 (67.6%) respondents agreed to write a letter of intent to declare hospice care or life-sustaining treatment for themselves if they had a terminal illness; there was no significant difference between the IPP and the non-IPP groups. However, 66.2% ($50.1 + 16.1\%$) of the respondents agreed or strongly agreed that they desired hospice care and did not want cardiopulmonary resuscitation when their family member's condition worsened. Compared to the IPP respondents, the non-IPP respondents had a higher ratio of disagreeing (strongly disagree or disagree) with wanting the patients to receive hospice care (18.8% vs 12.4%). However, compared to the non-IPP group, the IPP group had a higher percentage of individuals with no opinion (21.6% vs 14.5%) (Table 3).

HPCA-Related Factors Affecting Knowledge and Willingness

Regarding HPCA knowledge, the respondents had a higher IPP implementation score ($+8.68$, $P = .01$), more

female patients ($+3.48$, $P = .02$), older age (11.36 for patients ≥ 65 y old, $P = .044$), and higher monthly income ($+7.29$ for monthly income \$2,000–3,000, $P = .01$ and $+7.20$ for monthly income \geq \$3,000, $P = .02$); more respondents had heard of the HPCA ($+24.05$, $P < .001$), and more medical staff had been sharing information about the HPCA ($+5.43$, $P = .01$). Conversely, single (ie, never married) respondents had lower knowledge scores (-4.91 , $P = .049$). The related factors causing a greater higher willingness for hospice care were longer daily hours of mechanical ventilation support ($+0.02$, $P = .05$), female sex ($+0.2$, $P = .004$), being a child of the patients on PMV ($+0.45$, $P = .03$), and being grandchildren of the patients on PMV ($+1.04$, $P < .001$). However, the factors causing lower willingness for hospice care were patients being in respiratory care wards (-0.6 , $P < .001$), female sex (-0.13 , $P = .02$), patient age ≥ 55 y (-0.47 , $P < .01$), patients with thoracic deformity (-0.78 , $P = .02$), having heard of the HPCA cognition (-0.01 , $P < .001$), and medical staff having talked about the HPCA (-0.22 , $P = .002$) (Table 4).

Discussion

The purpose of the IPP design is to increase the turnover rate of intensive care beds. At the respiratory care center and respiratory care ward stages, the respiratory care team was formed to improve the ventilator liberation rate and quality of care of patients on PMV, in hopes to reduce overall medical care costs. The result was an increase in weaning rates of long-term ventilator-dependent patients. However improved survival in this population led to an increase in the number of patients receiving PMV, resulting in greater total medical cost at respiratory care ward,¹² even though only 29% of patients in the respiratory care ward are alert and oriented.¹⁶ The treatment cost for patients receiving PMV is expected to be > 5 times more than Taiwan's gross domestic product.³⁵ The overall hospitalization cost of patients on PMV in the United States in 2005 was the third highest Medicare medical expense. Medical expenses for patients receiving either short- or long-term mechanical ventilation are expected to increase 3–4-fold.³⁶ High medical costs do not lead to high medical efficiency, however, because the hospital mortality rate in patients on PMV is as high as 29–49%.³⁷ A total of 50% survive for > 1 year, and the number of elderly patients on PMV continues to increase.^{4,11,37,38} Cox et al³⁹ calculated that costs for patients on PMV increased by \$55,460 per life-year gained and by \$82,411 per quality-adjusted life year gained. Therefore, the Taiwan Health Insurance Agency hopes to strengthen the promotion of hospice and palliative care in the ICU, respiratory care center, and respiratory care ward to reduce the number of comatose patients on PMV. In our questionnaire, the respiratory care

KNOWLEDGE AND ACCEPTANCE OF HOSPICE CARE FOR PATIENTS ON PMV

Table 1. Demographics and Characteristics of Respondents With and Without IPP

Variables	All Respondents	Respondents Without IPP	Respondents With IPP	P
Gender				.67
Male	296 (49.25)	99 (47.83)	197 (50.00)	
Female	305 (50.75)	108 (52.17)	197 (50.00)	
Age, y				.19
≤ 34	43 (7.15)	9 (4.35)	34 (8.63)	
35–44	114 (18.97)	40 (19.32)	74 (18.78)	
45–54	198 (32.95)	65 (31.40)	133 (33.76)	
55–64	174 (28.95)	62 (29.95)	112 (28.43)	
≥ 65	72 (11.98)	31 (14.98)	41 (10.41)	
Mean age, y*	51.88 ± 11.84	53.30 ± 11.59	51.13 ± 11.92	
Level of education				.19
None	13 (2.16)	7 (3.38)	6 (1.52)	
Elementary	55 (9.15)	13 (6.28)	42 (10.66)	
Junior high school	106 (17.64)	40 (19.32)	66 (16.75)	
Senior high school	216 (35.94)	68 (32.85)	148 (37.56)	
College	187 (31.11)	71 (34.30)	116 (29.44)	
Graduate school	24 (3.99)	8 (3.86)	16 (4.06)	
Married				.24†
Yes	480 (80.00)	170 (82.13)	310 (78.88)	
No	90 (15.00)	28 (13.53)	62 (15.78)	
Divorce	16 (2.67)	3 (1.45)	13 (3.31)	
Widowed	11 (1.830)	6 (2.90)	5 (1.27)	
Cohabitation	3 (0.50)	0 (0)	3 (0.76)	
Monthly salary				.19
< \$1,000	154 (25.71)	45 (21.84)	109 (27.74)	
\$1,000–\$2,000	235 (39.23)	94 (45.63)	141 (35.88)	
\$2,000–\$3,000	125 (20.87)	42 (20.39)	83 (21.12)	
\$3,000–\$4,000	51 (8.51)	15 (7.28)	36 (9.16)	
≥ \$4,000	34 (5.68)	10 (4.85)	24 (6.11)	
Religion				.83
None	99 (16.47)	36 (17.39)	63 (15.99)	
Buddhism	186 (30.95)	62 (29.95)	124 (31.47)	
Taoism	252 (41.93)	84 (40.58)	168 (42.64)	
Kuan Tao	12 (2.00)	6 (2.90)	6 (1.52)	
Christian	23 (3.83)	9 (4.35)	14 (3.55)	
Catholic	7 (1.16)	2 (0.97)	5 (1.27)	
Islam	3 (0.50)	2 (0.97)	1 (0.25)	
Other	19 (3.16)	6 (2.90)	13 (3.30)	
Job				.60
None	236 (39.40)	79 (38.16)	157 (40.05)	
Part-time job	81 (13.52)	32 (15.46)	49 (12.50)	
Full-time job	282 (47.08)	96 (46.38)	186 (47.45)	
Relationship to patient				.42
Parent	41 (6.82)	8 (3.86)	33 (8.38)	
Couple	111 (18.47)	42 (20.29)	69 (17.51)	
Child	329 (54.74)	115 (55.56)	214 (54.31)	
Child-in-law	59 (9.82)	21 (10.14)	38 (9.64)	
Sibling	27 (4.49)	10 (4.83)	17 (4.31)	
Grandchild	17 (2.83)	7 (3.38)	10 (2.54)	
Other	17 (2.83)	4 (1.93)	13 (3.30)	
Mean monthly expense*	\$801.69 ± \$902.27	\$912.61 ± \$601.97	\$745.36 ± \$1,017.67	.01

Data are presented as n (%) unless otherwise noted. All subjects, N = 601; Non-IPP, n = 207; IPP, n = 394.

* Data are presented as mean ± SD.

† Fisher exact test.

IPP = integrated prospective payment program

KNOWLEDGE AND ACCEPTANCE OF HOSPICE CARE FOR PATIENTS ON PMV

Table 2. Demographics and Characteristics of Patients on PMV With and Without IPP

Variables	All Patients	Patients Without IPP	Patients With IPP	P
Gender				> .99
Male	304 (50.58)	105 (5.72)	199 (50.51)	
Female	297 (49.42)	102 (49.28)	195 (49.49)	
Age, y				.18
≤ 54	97 (16.14)	26 (12.56)	71 (18.02)	
55–64	91 (15.14)	26 (12.56)	65 (16.50)	
65–74	95 (15.81)	33 (15.94)	62 (15.74)	
75–84	187 (31.11)	70 (33.82)	117 (29.70)	
≥ 85	131 (21.80)	52 (25.12)	79 (20.05)	
Mean age, y*	70.76 ± 17.22	73.15 ± 15.98	69.51 ± 17.72	
Comorbidity				
Hypertension	326 (54.24)	119 (57.49)	207 (52.54)	.28
Heart disease	198 (32.95)	75 (36.23)	123 (31.22)	.25
Diabetes	189 (31.45)	63 (3.43)	126 (31.98)	.77
Stroke	127 (21.13)	43 (2.77)	84 (21.32)	.96
Chronic kidney disease	59 (9.82)	19 (9.18)	40 (10.15)	.81
Chronic liver disease	25 (4.16)	8 (3.86)	17 (4.31)	.96
Mental status				.26
Coma	194 (32.28)	66 (31.88)	128 (32.49)	
Semi-coma	174 (28.95)	68 (32.85)	106 (26.90)	
Alert	233 (38.77)	73 (35.27)	160 (40.61)	
Cause of respiratory failure				.02†
Chronic lung disease	131 (21.80)	51 (24.64)	80 (20.30)	
Central neuropathy	185 (30.78)	60 (28.99)	125 (31.73)	
Catastrophic illnesses	209 (34.78)	83 (4.10)	126 (31.98)	
Post-surgery	35 (5.82)	6 (2.90)	29 (7.36)	
Muscle neuropathy	27 (4.49)	6 (2.90)	21 (5.33)	
Thoracic deformity	7 (1.16)	0 (0)	7 (1.78)	
Other	7 (1.16)	1 (.48)	6 (1.52)	
Type of mechanical ventilation				.79
Invasive	524 (87.19)	182 (87.92)	342 (86.80)	
Noninvasive	77 (12.81)	25 (12.08)	52 (13.20)	
Ownership of ventilator				< .001
Hospital/institution	561 (93.34)	176 (85.02)	385 (97.72)	
Vendor lease	32 (5.32)	23 (11.11)	9 (2.28)	
Self-purchase	8 (1.33)	8 (3.86)	0 (0)	
Place of questionnaire response				< .001
Medical center	131 (21.80)	27 (13.04)	104 (26.40)	
Regional hospital	165 (27.45)	60 (28.99)	105 (26.65)	
District hospital	154 (25.62)	93 (44.93)	61 (15.48)	
Long-term care facility	73 (12.15)	24 (11.59)	49 (12.44)	
Others	78 (12.98)	3 (1.45)	75 (19.04)	
Duration mechanical ventilation, h*	21.47 ± 5.39	22.49 ± 4.44	20.93 ± 5.77	< .001
Duration of sleep, h				.004†
0–6	1 (0.17)	1 (0.48)	0 (0)	
7–12	37 (6.16)	5 (2.42)	32 (8.12)	
13–18	26 (4.33)	6 (2.90)	20 (5.08)	
19–24	537 (89.35)	195 (94.20)	342 (86.80)	
Try weaning within 1 month	385 (64.06)	129 (62.32)	256 (64.97)	.58
Join IPP and waive copayment	494 (82.20)	143 (69.08)	351 (89.09)	< .001

Data are presented as n (%) unless otherwise noted. All subjects, N = 601; Non-IPP, n = 207; IPP, n = 394.

* Data are presented as mean ± SD.

† Fisher exact test.

IPP = integrated prospective payment program

KNOWLEDGE AND ACCEPTANCE OF HOSPICE CARE FOR PATIENTS ON PMV

Table 3. Knowledge and Willingness of Hospice Palliative Care in Respondents (Family Members as Main Caregivers)

Variables	All Respondents	Respondents Without IPP	Respondents With IPP	P
Have you ever heard of hospice palliative care?				.30
No	177 (29.45)	67 (32.37)	110 (27.92)	
Yes	424 (70.55)	140 (67.63)	284 (72.08)	
Did medical staff introduce hospice palliative care?				.46
No	346 (57.67)	114 (55.34)	232 (58.88)	
Yes	254 (42.33)	92 (44.66)	162 (41.12)	
Total knowledge score (0–100)*				
Total	51.35 ± 29.50	51.21 ± 26.22	51.43 ± 31.12	.73
ICU	47.00 ± 31.75	50.83 ± 27.22	44.44 ± 34.35	.31
Respiratory care center	48.08 ± 29.35	51.04 ± 26.77	46.11 ± 30.94	.39
Respiratory care ward	53.92 ± 30.79	49.58 ± 26.84	56.81 ± 33.00	.17
Home care	56.37 ± 24.91	56.02 ± 21.75	56.45 ± 25.63	.80
I can accept that my family member (PMV patient) will receive hospice palliative care instead of continuing intensive care when the condition is unrecoverable.				.03
Strongly Agree	97 (16.14)	38 (18.36)	59 (14.97)	
Agree	301 (50.08)	100 (48.31)	201 (51.02)	
Neutral	115 (19.13)	30 (14.49)	85 (21.57)	
Disagree	65 (10.82)	32 (15.46)	33 (8.38)	
Strongly Disagree	23 (3.83)	7 (3.38)	16 (4.06)	
Will you be willing to sign the advance informed consent form for hospice palliative care in the future?				.81
No	195 (32.45)	69 (33.33)	126 (31.98)	
Yes	406 (67.55)	138 (66.67)	268 (68.02)	

Data are presented as n (%) unless otherwise noted. All subjects, N = 601; Non-IPP, n = 207; IPP, n = 394.

* Data are presented as mean ± SD.

PMV = prolonged mechanical ventilation

IPP = integrated prospective payment program

ward and home-based PMV respondents had higher hospice care knowledge than the ICU and respiratory care center respondents, regardless of whether their family members were enrolled in IPP, although there was no significant difference between them. However, the promotion of hospice and palliative care among patients on PMV and their families (ie, in respiratory care wards and in home care) has produced some minor effects.

The HPCA was enacted and promulgated in June 2000 in Taiwan; however, some issues regarding the order in which family members were given priority to have the authority to make medical decisions on behalf of a patient (eg, via power of attorney) have caused disputes. In response, the HPCA was amended 3 times from 2000 to 2013.²⁰ Whereas the literature reported that 60–80% of people know about the HPCA, only 50–60% understood its contents.^{40,41} The factors affecting the respondents' knowledge and willingness related to hospice care were complicated and included sex, age, marriage, income, education level, and knowledge of hospice care.^{41–43} Individuals who were female, younger, married with higher income, and had higher education attainment had greater knowledge of hospice care.^{41,42} In our study, the results

revealed that the IPP intervention, female patients' families, and coma status were related to higher knowledge scores. However, respondents who were older (≥ 65 y), married, had higher income, and were told about the HPCA by medical staff also had higher knowledge scores.⁴⁴ These results may be related to an aging population and a growing dependence ratio in Taiwan,⁴⁴ given that the average ages of the respondents and patients on PMV in our study were 51.9 y and 70.8 y respectively.

A variety of factors influence the hospice care decision-making process, such as health care expenditure, legal risks, religion, and the experience and life attitudes of physicians, families, or surrogates.^{28,41,45–48} Our study results indicate that patients staying in respiratory care centers, male patients' families, female respondents, and children and grandchildren of patients had a greater willingness to declare their desire to have hospice care or to withhold/withdraw life-sustaining treatment. In addition, only 28% of terminal cancer patients in central Taiwan had signed a do-not-resuscitate order themselves; most of these decisions were made by family members.³⁴ A total of 42.3% of the respondents agreed that medical staff had discussed hospice care with them, although there was no difference

KNOWLEDGE AND ACCEPTANCE OF HOSPICE CARE FOR PATIENTS ON PMV

Table 4. Factors Affecting the Knowledge and Willingness of HPCA in Family Members as Main Caregivers of Patients on PMV

Variable	Knowledge		Willingness	
	Coefficients (95% CI)	P	Coefficients (95% CI)	P
Patients				
IPP participant (Ref. Non-IPP)	8.68 (2.26–15.09)	.008	0 (–0.22–0.22)	.99
Care unit (Ref. ICU)				
Respiratory care center	–1.9 (–6.23–2.42)	.39	–0.05 (–0.29–0.19)	.69
Respiratory care ward	2.61 (–4.3–9.51)	.46	–0.6 (–0.86 to –0.33)	< .001
Home care	2.62 (–5.22–10.47)	.51	–0.29 (–0.64–0.05)	.09
Gender (Ref. male)	3.48 (0.66–6.29)	.02	–0.13 (–0.24 to –0.02)	.02
Age (Ref. ≤ 54 y)				
55–64	–0.1 (–8.25–8.05)	.98	–0.47 (–0.73 to –0.21)	< .001
65–74	–1.65 (–12.19–8.89)	.76	–0.83 (–1.15 to –0.51)	< .001
75–84	2.82 (–7.69–13.33)	.60	–0.68 (–1.02 to –0.33)	< .001
≥ 85	3.25 (–7.49–14.00)	.55	–0.78 (–1.13 to –0.44)	< .001
Cause of PMV (Ref. CPD)				
Central neuropathy	0.97 (–4.74–6.68)	.74	0.01 (–0.18–0.19)	.93
Catastrophic illnesses	0.75 (–4–5.51)	.76	0.06 (–0.11–0.24)	.49
Post-surgery	–1.42 (–8.81–5.96)	.71	–0.03 (–0.32–0.26)	.85
Muscle nerve disease	0.36 (–7.21–7.93)	.93	0.2 (–0.08–0.49)	.17
Chest deformity	–6.05 (–21.41–9.32)	.44	–0.78 (–1.31 to –0.25)	.004
Other	–27.18 (–38.94 to –15.42)	< .001	0.29 (–0.17–0.76)	.21
Type of ventilator (Ref. invasive)				
Noninvasive	2.72 (–4.26–9.7)	.45	–0.11 (–0.35–0.13)	.39
Mean PMV use, h/d	–0.17 (–0.56–0.23)	.41	0.02 (0.01–0.03)	.005
Conscious level (Ref. Coma)				
Unclear	–4.42 (–9.36–0.52)	.08	0.03 (–0.13–0.2)	.71
Clear	–6.87 (–10.78 to –2.97)	< .001	–0.11 (–0.27–0.05)	.19
Respondents				
Gender (Ref. male)	2.83 (–0.48–6.13)	.09	0.2 (0.06–0.33)	.004
Age (Ref. ≤ 34 y)				
35–44	7.63 (–1.26–16.53)	.09	–0.22 (–0.48–0.03)	.09
45–54	6.34 (–3.26–15.94)	.20	–0.19 (–0.46–0.07)	.15
55–64	6.96 (–3.51–17.42)	.19	–0.03 (–0.32–0.26)	.84
≥ 65	11.36 (0.31–22.40)	.044	0.29 (–0.07–0.65)	.12
Education (Ref. ≤ Elementary)				
Junior high	4.41 (–1.49–10.31)	.14	–0.04 (–0.24–0.16)	.69
Senior high	–3.46 (–9.06–2.14)	.23	0.05 (–0.18–0.28)	.68
University	–1.4 (–7.89–5.10)	.67	–0.17 (–0.46–0.11)	.23
Graduate school	3.52 (–7.81–14.86)	.54	0.01 (–0.37–0.4)	.95
Marital status (Ref. Married)				
Single (ie, never married)	–4.91 (–9.8 to –0.01)	.049	0.28 (–0.01–0.57)	.057
Formerly married	3.7 (–6.48–13.87)	.477	–0.23 (–0.57–0.12)	.20
Monthly total household income (Ref. ≤ \$1,000)				
1,000–2,000	2.96 (–1.37–7.29)	.18	0.12 (–0.03–0.28)	.12
2,000–3,000	7.29 (1.72–12.87)	.01	0.16 (–0.01–0.34)	.07
≥ 3,000	7.20 (1.12–13.28)	.02	0.15 (–0.07–0.38)	.18
Religion (Ref. None)				
Buddhism	–4.93 (–10.08–0.22)	.061	0 (–0.19–0.19)	.99
Taoism	4.40 (–1.06–9.86)	.115	–0.11 (–0.26–0.04)	.17
Christianity	0.07 (–7.65–7.78)	.986	–0.26 (–0.63–0.12)	.18
Other	–0.8 (–8.16–6.57)	.831	0.1 (–0.24–0.44)	.56

(continued)

Table 4. Continued

Variable	Knowledge		Willingness	
	Coefficient (95% CI)	<i>P</i>	Coefficient (95% CI)	<i>P</i>
Relationship to patient (Ref. Parents)				
Couple	0.93 (−11.63–13.49)	.89	0.27 (−0.08–0.63)	.13
Child	4.30 (−10.16–18.76)	.56	0.45 (0.06–0.84)	.03
Child-in-law	0.76 (−14.76–16.28)	.92	0.13 (−0.28–0.55)	.53
Sibling	10.44 (−0.48–21.36)	.061	−0.23 (−0.59–0.13)	.21
Grandchild	8.34 (−13.26–29.95)	.45	1.04 (0.46–1.62)	< .001
Other	0.63 (−14.23–15.49)	.93	0.73 (0.28–1.18)	.002
Aware of the HPCA (Ref. No)	24.05 (20.5–27.61)	< .001	−0.11 (−0.27–0.06)	.21
Medical staff introduced hospice care (Ref. No)	5.43 (1.18–9.69)	.01	−0.22 (−0.36 to −0.08)	.002
HPCA knowledge	NA	NA	−0.01 (−0.01–0)	< .001

HPCA = Hospice Palliative Care Act
 PMV = prolonged mechanical ventilation
 IPP = integrated prospective payment program
 Ref. = reference group
 CPD = chronic pulmonary disease
 NA = not applicable

between the IPP groups (IPP vs non-IPP: 41.1% vs 44.67%), a result that may have been influenced by physician background, legal risks, financial burden considerations, and culture.^{28,46}

Phua et al⁴⁶ reported that Asian physicians believed that they exposed themselves to legal risk if they applied limitations to life-sustaining treatment. However, only 60–70% of nursing staff understood the HPCA after an HPCA educational training program.^{48,49}

The willingness to agree to hospice care is relatively high, which may be related to the attitudes of medical staff and incomplete legislation.²⁰ At the time, legislation required all relatives to sign, which made it difficult for doctors to perform hospice care. Other studies have shown that doctors' attitudes are also an important factor. When faced with disease progression or drug treatment becomes ineffective, doctors in Asian countries are less likely to sign execution Do-not-resuscitation than in Europe and the United States.²² One study found that while 70.2% of Asian physicians were almost always or often willing to withhold life-sustaining treatment, only 20.7% almost always or often did so when the patient showed no change in their recovery because of concern for legal risks (adjusted odds ratio, 1.92). Even in cases of severe hypoxic-ischemic encephalopathy following cardiac arrest, 53.8% of Asian physicians would continue to maintain mechanical ventilation.⁴⁶ Yeh¹⁶ found that most patients undergoing PMV in a long-term care unit were elderly and in an unconscious state;¹⁶ therefore, the related medical decisions were frequently made by relatives. Studies have shown that patients on PMV generally have a poor quality of life,^{35,50} higher in-hospital and post-discharge mortality rates, higher

health care costs,⁵¹ and greater family burdens.¹⁹ Our study revealed that only 38.8% of patients on PMV were in clear consciousness. There was no significant difference between the non-IPP and the IPP groups; therefore, the relevant medical decisions were mostly determined by their families. In this study, 67.6% of the respondents were willing to write a letter for hospice care or withholding/withdrawing life-sustaining treatment in cases of terminal illness, although this study shows that the increased awareness of medical personnel involved in the intervention of hospice care does not mean that there is a high willingness for implementation. More encouragement and support may be required.

Limitations

There are several limitations to consider when interpreting these study results. First, the IPP has been fully implemented, and it is not possible to conduct separate questionnaires targeting families of patients who have or have not joined the IPP. The only way to distinguish between them is by noting whether a medical institution is in the IPP system, which may make it impossible to accurately reflect differences in the effectiveness of the IPP. Second, PMV medical expenses for home care patients only estimate health insurance declaration fees and cannot give an estimate of family out-of-pocket expenses, such as self-purchased oxygen concentrators, suction machines, and electrical fees. Therefore, medical expenses may be underestimated.

Conclusions

Our findings indicate that the IPP group had greater knowledge of the HPCA than the non-IPP group. After the introduction of the HPCA by medical staff, the respondents had greater knowledge of the HPCA. However, respondents with high hospice care knowledge did not necessarily have high willingness. There was no significant difference between the IPP and the non-IPP respondents in terms of their willingness to write a letter of intent regarding the choice of hospice care or life-sustaining treatment. However, there was a significant difference between the IPP and the non-IPP groups in whether their relatives chose hospice care or life-sustaining treatment. We suggest that medical staff encourage people to express their final willingness to support life-sustaining treatment and to write a letter of intent regarding the choice of hospice care or life-sustaining treatment to avoid the dilemma of requiring family members to make these choices when patients are unable to do so themselves.

REFERENCES

1. MacIntyre NR, Epstein SK, Carson S, Scheinhorn D, Christopher K, Muldoon S. Management of patients requiring prolonged mechanical ventilation: report of a NAMDRC consensus conference. *Chest* 2005; 128(6):3937-3954.
2. National Health Insurance Administration Ministry of Health and Welfare. Integrated delivery system with a prospective payment program for ventilator-dependent patients. 2000. Available at: http://www.nhi.gov.tw/webdata/webdata.aspx?menu=8&menu_id=498&webdata_id=3048. Accessed January 21, 2017.
3. Kahn JM, Le T, Angus DC, Cox CE, Hough CL, White DB, et al. The epidemiology of chronic critical illness in the United States. *Crit Care Med* 2015;43(2):282-287.
4. Lone NI, Walsh TS. Prolonged mechanical ventilation in critically ill patients: epidemiology, outcomes and modelling the potential cost consequences of establishing a regional weaning unit. *Crit Care* 2011; 15(2):R102.
5. Loss SH, de Oliveira RP, Maccari JG, Savi A, Boniatti MM, Hetzel MP, et al. The reality of patients requiring prolonged mechanical ventilation: a multicenter study. *Rev Bras Ter Intensiva* 2015;27(1): 26-35.
6. Rose L, Fowler RA, Fan E, Fraser I, Leasa D, Mawdsley C, et al. Prolonged mechanical ventilation in Canadian intensive care units: a national survey. *J Crit Care* 2015;30(1):25-31.
7. Liu CJ, Chu CC, Chen W, Cheng WE, Shih CM, Tsai YS, et al. Impact of Taiwan's integrated prospective payment program on prolonged mechanical ventilation: a 6-year nationwide study. *Respir Care* 2013;58(4):676-682.
8. Li J, Zhan QY, Wang C. Survey of prolonged mechanical ventilation in intensive care units in mainland China. *Respir Care* 2016;61(9): 1224-1231.
9. Scheinhorn DJ, Hassenpflug MS, Votto JJ, Chao DC, Epstein SK, Doig GS, et al. Post-ICU mechanical ventilation at 23 long-term care hospitals: a multicenter outcomes study. *Chest* 2007;131(1):85-93.
10. Scheinhorn DJ, Hassenpflug MS, Votto JJ, Chao DC, Epstein SK, Doig GS, et al. Ventilator-dependent survivors of catastrophic illness transferred to 23 long-term care hospitals for weaning from prolonged mechanical ventilation. *Chest* 2007;131(1):76-84.
11. Lin MS, Yan YH, Wang JD, Lu HM, Chen L, Hung MC, et al. Improved survival for an integrated system of reduced intensive respiratory care for patients requiring prolonged mechanical ventilation. *Respir Care* 2013;58(3):517-524.
12. Liu CJ, Kung PT, Chu CC, Chou WY, Wang YH, Tsai WC. Propensity score-matching analyses on the effectiveness of integrated prospective payment program for patients with prolonged mechanical ventilation. *Health Policy* 2018;122(9):970-976.
13. Polverino E, Nava S, Ferrer M, Ceriana P, Cline E, Spada E, et al. Patients' characterization, hospital course and clinical outcomes in five Italian respiratory intensive care units. *Intensive Care Med* 2010; 36(1):137-142.
14. Zilberberg MD, de Wit M, Pirone JR, Shorr AF. Growth in adult prolonged acute mechanical ventilation: implications for healthcare delivery. *Crit Care Med* 2008;36(5):1451-1455.
15. Huang HS, Liu SS, Shen MC. Health checkup report on the National Health Insurance. Taipei, Taiwan: Control Yuan, 2011.
16. Yeh L. Characteristics of institutionalized ventilator dependent client in Tainan Area. *Thorac Med* 2001;16(4):236-243.
17. Douglas SL, Daly BJ, Brennan PF, Gordon NH, Uthris PJC. Hospital readmission among long-term ventilator patients. *Chest* 2001;120(4): 1278-1286.
18. Chiang L-L, Wu C-P, Wang L-Y, Wu Y-T. Functional status and quality of life in ventilator-dependent patients. *Formosan J Phys Ther* 2004;29(1):40-47.
19. Wu Y-H, Tseng Y-H. The lived experience of family caregivers caring for ventilator-dependent patients at home. *J Long-Term Care* 2009;13(2):169-189.
20. Hospice Palliative Care Act. Legislative Yuan, Republic of China 2013. Available at: <https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0020066>. Accessed June 14, 2018.
21. World Health Organization. WHO Definition of Palliative Care. Available at: <http://www.who.int/cancer/palliative/definition/en/>. Accessed June 14, 2018.
22. Yaguchi A, Truog RD, Curtis JR, Luce JM, Levy MM, Mélot C, et al. International differences in end-of-life attitudes in the intensive care unit: results of a survey. *Arch Intern Med* 2005;165(17):1970-1975.
23. Vincent JL. European attitudes towards ethical problems in intensive care medicine: results of an ethical questionnaire. *Intensive Care Med* 1990;16(4):256-264.
24. Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire. *Crit Care Med* 1999; 27(8):1626-1633.
25. Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, Lenoir S, et al. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *EURONIC Study Group. Lancet* 2000;355(9221):2112-2118.
26. Kubler A, Adamik B, Lipinska-Gediga M, Kedziora J, Strozecki L. End-of-life attitudes of intensive care physicians in Poland: results of a national survey. *Intensive Care Med* 2011;37(8):1290-1296.
27. Frost DW, Cook DJ, Heyland DK, Fowler RA. Patient and health-care professional factors influencing end-of-life decision-making during critical illness: a systematic review. *Crit Care Med* 2011;39(5): 1174-1189.
28. Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, et al. Withholding and withdrawal of life-sustaining treatments in low-middle-income versus high-income Asian countries and regions. *Intensive Care Med* 2016;42(7):1118-1127.
29. Latour JM, Fulbrook P, Albarran JW. EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care. *Nurs Crit Care* 2009;14(3):110-121.

30. Coombs M, Fulbrook P, Donovan S, Tester R, deVries K. Certainty and uncertainty about end of life care nursing practices in New Zealand intensive care units: a mixed methods study. *Aust Crit Care* 2015;28(2):82-86.
31. Badir A, Topcu I, Turkmen E, Goktepe N, Miral M, Ersoy N, et al. Turkish critical care nurses' views on end-of-life decision making and practices. *Nurs Crit Care* 2016;21(6):334-342.
32. Razban F, Iranmanesh S, Aliabadi HE, Forouzi MA. Critical care nurses' attitude towards life-sustaining treatments in South East Iran. *World J Emerg Med* 2016;7(1):59-64.
33. Lee F-N. Who gives informed consent on behalf of emergency patients? *Taiwan J Pub Health* 2010;29(1):65-75.
34. Yang F-H, Lee S-C, Wang R-Y, Yang S-K, Lin S-Y, Chen J-H. The factors influencing the behavior intention of do-not-resuscitate requests for families. *Cheng Ching Med J* 2016;12(1):30-39.
35. Hung MC, Lu HM, Chen L, Lin MS, Chen CR, Yu CJ, et al. Cost per QALY (quality-adjusted life year) and lifetime cost of prolonged mechanical ventilation in Taiwan. *PLoS One* 2012;7(9):e44043.
36. Donahoe MP. Current venues of care and related costs for the chronically critically ill. *Respir Care* 2012;57(6):867-886.
37. Damuth E, Mitchell JA, Bartock JL, Roberts BW, Trzeciak S. Long-term survival of critically ill patients treated with prolonged mechanical ventilation: a systematic review and meta-analysis. *Lancet Respir Med* 2015;3(7):544-553.
38. Jubran A, Grant BJ, Duffner LA, Collins EG, Lanuza DM, Hoffman LA, et al. Long-term outcome after prolonged mechanical ventilation: a long-term acute-care hospital study. *Am J Respir Crit Care Med* 2019.
39. Cox CE, Carson SS, Govert JA, Chelluri L, Sanders GD. An economic evaluation of prolonged mechanical ventilation. *Crit Care Med* 2007;35(8):1918-1927.
40. Lin C-P, Wu C-L, Wang W-Y, Chu C-S, Yang H-T, Wang T-Y. Cancer care capability of Taipei City Hospital. *Taipei City Med J* 2005;2(5):445-453.
41. Huang H-M, Kuo B-J, Hu C-C, Hsieh Y-L, Hwang S-F. A community study of the level and the influential factors of palliative care knowledge. *Taiwan J Hospice Pall Care* 2005;10(4):371-383.
42. Wang S-C. People's recognition tendency and concerned factors in hospice care. *Taiwan J Hospice Pall Care* 2007;12(1):44-55.
43. Rothchild E. Family dynamics in end-of-life treatment decisions. *Gen Hosp Psychiatry* 1994;16(4):251-258.
44. Department of Statistics, Ministry of the Interior. The Rank of Life Expectancy at Birth by Country, 2013. Available at: https://www.moi.gov.tw/stat/node.aspx?cate_sn=&belong_sn=5992&sn=6176. Accessed June 14, 2018.
45. Tang ST, Wen FH, Liu LN, Chiang MC, Lee SC, Chou MC, et al. A decade of changes in family caregivers' preferences for life-sustaining treatments for terminally ill cancer patients at end of life in the context of a family-oriented society. *J Pain Symptom Manage* 2016;51(5):907-915.
46. Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, et al. Withholding and withdrawal of life-sustaining treatments in intensive care units in Asia. *JAMA Intern Med* 2015;175(3):363-371.
47. Monteiro F. Family reliance on physicians' decisions in life-sustaining treatments in acute-on-chronic respiratory diseases in a respiratory ICU: a single-center study. *Respir Care* 2014;59(3):411-419.
48. Cheng S-F, Liu H-E, Fang C-C, Wan G-H. Factors associated with the knowledge of "Hospice and Palliative Care Act" and attitude towards "do not resuscitate" among the medical staff in emergency department. *Formosan J Med* 2010;14(2):124-132.
49. Tsai L-Y, Li I-F, Liu C-P, Lai Y-L, Change T-Y, Tu C-T. The study for the effect of natural death act educational program. *Taiwan J Hospice Pall Care* 2003;8(4):364-380.
50. Chiumello D, Coppola S, Froio S, Gotti M. What's next after ARDS: long-term outcomes. *Respir Care* 2016;61(5):689-699.
51. Hill AD, Fowler RA, Burns KE, Rose L, Pinto RL, Scales DC. Long-term outcomes and health care utilization after prolonged mechanical ventilation. *Ann Am Thorac Soc* 2017;14(3):355-362.